

# NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

## HIGHLY SPECIALISED TECHNOLOGY EVALUATION PROGRAMME

### Equality impact assessment – Guidance development

#### HST Strimvelis for treating severe combined immunodeficiency caused by adenosine deaminase deficiency

The impact on equality has been assessed during this evaluation according to the principles of the NICE equality scheme.

#### Consultation

1. Have the potential equality issues identified during the scoping process been addressed by the Committee, and, if so, how?

Consultees noted that the prevalence of severe combined immunodeficiency caused by adenosine deaminase deficiency (ADA-SCID) varies widely between populations, and in England this condition is most common in people from Irish Traveller and Somalian family origins.

Attendees at the scoping workshop stated that the availability of HLA-matched stem cell donors also varies between populations, and is lower in people of Somalian family origin. Health outcomes are worse in people for whom an HLA-matched related donor is not available, and this technology may be particularly beneficial as HLA matching decreases.

The committee considered that access to Strimvelis may reduce the disparity in wait times for transplantation between different ethnic groups, but acknowledged that there are no data on the size of this potential impact. The committee concluded that this potential equality issue should be qualitatively taken into consideration in its decision-making.

2. Have any other potential equality issues been raised in the submissions, expert statements or independent academic report, and, if so, how has the Committee addressed these?

No other potential equality issues been raised

3. Have any other potential equality issues been identified by the Committee, and, if so, how has the Committee addressed these?

No other potential equality issues been raised

4. Do the preliminary recommendations make it more difficult in practice for a specific group to access the technology compared with other groups? If so, what are the barriers to, or difficulties with, access for the specific group?

No

5. Is there potential for the preliminary recommendations to have an adverse impact on people with disabilities because of something that is a consequence of the disability?

No

6. Are there any recommendations or explanations that the Committee could make to remove or alleviate barriers to, or difficulties with, access identified in questions 4 or 5, or otherwise fulfil NICE's obligations to promote equality?

Not applicable

7. Have the Committee's considerations of equality issues been described in the evaluation consultation document, and, if so, where?

Section 4.37 of the Evaluation Consultation Document

**Approved by Associate Director (name):** Sheela Upadhyaya

**Date:** 10 October 2017

## **Final evaluation determination**

(when an ECD issued)

1. Have any additional potential equality issues been raised during the consultation, and, if so, how has the Committee addressed these?
No

2. If the recommendations have changed after consultation, are there any recommendations that make it more difficult in practice for a specific group to access the technology compared with other groups? If so, what are the barriers to, or difficulties with, access for the specific group?
No change to the recommendations

3. If the recommendations have changed after consultation, is there potential for the recommendations to have an adverse impact on people with disabilities because of something that is a consequence of the disability?
n/a

4. If the recommendations have changed after consultation, are there any recommendations or explanations that the Committee could make to remove or alleviate barriers to, or difficulties with, access identified in questions 2 and 3, or otherwise fulfil NICE's obligations to promote equality?
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n/a

5. Have the Committee's considerations of equality issues been described in the final evaluation determination, and, if so, where?

Section 4.37 of the Final Evaluation Determination

**Approved by Centre or Programme Director (name):** Meindert Boysen

**Date:** 27 December 2017